

**SPECIALIZED CLINICAL SERVICES****TECHNOLOGY DEPENDENT CHILDREN****INTRODUCTION**

The last several decades have seen a surge in the number of children with special health care needs, currently estimated to account for 13% of all children and for 70% of all child health care expenditures. Many of these children require some form of technological assistance to compensate for loss or impairment of one or more vital functions. Advances in intensive care practices and improved survival have resulted in an increase in the number and complexity of technology dependent infants and children being cared for both on acute inpatient floors and at home. Commonly used devices include gastrostomy and jejunostomy tubes with and without fundoplication, ventricular shunts, baclofen pumps, indwelling central venous catheters, tracheostomies, and various forms of non-invasive ventilation. Pediatric hospitalists frequently encounter these technology dependent children, and therefore must have a working knowledge of these devices and technologies, as well as an understanding of the associated challenges that may arise both in and out of the hospital and within the continuum of the child's life. Care coordination for these children has been reported to result in clinical and process improvements, reduced health care costs, and improved family/caregiver satisfaction. The importance of these issues is reflected in the work of the National Center of Medical Home Initiatives for Children with Special Needs and in an American Academy of Pediatrics policy statement, "The Medical Home."

**KNOWLEDGE**

*Pediatric hospitalists should be able to:*

- List the indications for placement and removal of common enteral feeding devices such as nasogastric, nasojejunal, percutaneous gastrostomy, surgically performed gastrostomy tube with and without fundoplication, and gastro-jejunal tube.
- Discuss the utility of evaluation techniques for disorders that may require these interventions, attending to therapist, developmental, and radiographic evaluations.
- Compare and contrast the risks, benefits, and alternatives of various modes of long term intravenous access and externally implanted, totally implanted, and percutaneously implanted catheter types such as Broviac, Mediport, PICC and others.
- Discuss the medical and ethical considerations for the initiation and removal of chronic respiratory support, including interventions such as tracheostomy, bilevel positive airway pressure, continuous positive airway pressure, and others.
- Review common acute problems relating to specific medical devices, such as central venous catheter infection and enteral feeding tube dysfunction, and discuss the diagnostic evaluation and treatment of these problems.
- Compare and contrast nosocomial infection risk in patients chronically dependent on technology compared to hospitalized patients with acute, limited technology device use.
- State how the National Patient Safety Goals relate to the care of these patients, and describe how best practices around these goals are applied when rendering care.
- Summarize how common acute systemic illnesses affect the technology dependent child from both short and long term perspectives.
- Define pain, anxiety, fear, and depression in patients undergoing evaluation or manipulation of medical devices and explain the interrelationship between them.
- Describe the social, emotional and fiscal impact of assessment, initiation, and/or removal of medical devices on the family/caregiver.
- Discuss the technical and practical aspects of homecare delivery for technology dependent children and the family/caregiver.
- Describe issues or concerns which should prompt referrals to the ethics committee, hospice, or palliative care services.
- List the community and educational resources for technology dependent children.

**SKILLS**

*Pediatric hospitalists should be able to:*

- Create a comprehensive discharge plan including device care and explicit emergency response instructions for the family/caregiver.
- Coordinate care with subspecialists and the primary care provider maintaining the medical home model.

- Write a comprehensive yet succinct summary appeal letter to insurers if medically indicated services are denied.
- Demonstrate clinical proficiency in basic care of common medical devices as well as emergency management of common complications such as accidental tracheostomy decannulation or gastrostomy tube extrusion.
- Clinically evaluate fit and function of devices, attending to the child's age and developmental stage.
- Implement and adjust common medications used in conjunction with medical devices.
- Coordinate end-of-life interdisciplinary discussions between appropriate subspecialists, teams, primary care provider, and the family/caregiver, and implement this care when appropriate.

## ATTITUDES

*Pediatric hospitalists should be able to:*

- Provide leadership to an interdisciplinary team, reflecting awareness that hospitalization is a phase of longitudinal care.
- Model communication skills that are clear, compassionate, and sensitive to religious and cultural values of patients and the family/caregiver.
- Advocate for medically-appropriate devices and the support services necessary to maintain these.
- Recognize the need to continually assess patient and family/caregiver needs relating to technology dependence within the context of developmental and quality of life concerns.
- Collaborate with subspecialists and the primary care provider to ensure coordinated longitudinal care for technology dependent children.

## SYSTEMS ORGANIZATION AND IMPROVEMENT

*In order to improve efficiency and quality within their organizations, pediatric hospitalists should:*

- Lead, coordinate or participate in the development and implementation of systems within the hospital to ensure comprehensive patient and family/caregiver-centered care for the technology dependent child.
- Lead, coordinate or participate in quality improvement initiatives to improve care for the technology dependent child.
- Collaborate with local, state, and national political groups to educate and champion for equitable access to current technology for all of these children, and for research funding to enhance their future.